

# Early experience with medical assistance in dying in Ontario, Canada: a cohort study

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## ABSTRACT

**BACKGROUND:** Medical assistance in dying (MAiD) was legalized across Canada in June 2016. Some have expressed concern that patient requests for MAiD might be driven by poor access to palliative care and that social and economic vulnerability of patients may influence access to or receipt of MAiD. To examine these concerns, we describe Ontario's early experience with MAiD and compare MAiD decedents with the general population of decedents in Ontario.

**METHODS:** We conducted a retrospective cohort study comparing all MAiD-related deaths with all deaths in Ontario, Canada, between June 7, 2016, and Oct. 31, 2018. Clinical and demographic characteristics were collected for all MAiD decedents and compared with those of all Ontario decedents when possible. We used logistic regres-

sion analyses to describe the association of demographic and clinical factors with receipt of MAiD.

**RESULTS:** A total of 2241 patients (50.2% women) were included in the MAiD cohort, and 186 814 in the general Ontario decedent cohort. Recipients of MAiD reported both physical (99.5%) and psychologic suffering (96.4%) before the procedure. In 74.4% of cases, palliative care providers were involved in the patient's care at the time of the MAiD request. The statutory 10-day reflection period was shortened for 26.6% of people. Compared with all Ontario decedents, MAiD recipients were younger (mean 74.4 v. 77.0 yr, standardized difference 0.18); more likely to be from a higher income quintile (24.9% v. 15.6%, standardized difference across quintiles 0.31); less likely to reside in an institution (6.3% v. 28.0%,

standardized difference 0.6); more likely to be married (48.5% v. 40.6%) and less likely to be widowed (25.7% v. 35.8%, standardized difference 0.34); and more likely to have a cancer diagnosis (64.4% v. 27.6%, standardized difference 0.88 for diagnoses comparisons).

**INTERPRETATION:** Recipients of MAiD were younger, had higher income, were substantially less likely to reside in an institution and were more likely to be married than decedents from the general population, suggesting that MAiD is unlikely to be driven by social or economic vulnerability. Given the high prevalence of physical and psychologic suffering, despite involvement of palliative care providers in caring for patients who request MAiD, future studies should aim to improve our understanding and treatment of the specific types of suffering that lead to a MAiD request.

**M**edical assistance in dying (MAiD) was legalized throughout Canada in June 2016.<sup>1,2</sup> Under Canadian law, MAiD is permissible for competent adults who have a serious and incurable illness, disease or disability; who are in an advanced state of irreversible decline in capability; whose illness, disease or disability or state of decline causes them enduring physical or psychologic suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and whose natural death has become reasonably foreseeable, taking into account all of their medical

circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining. Medical assistance in dying may be self-administered or clinician-administered, and may be provided by a medical or nurse practitioner. By Oct. 31, 2018, 6749 Canadians had received MAiD,<sup>3</sup> accounting for 1.1% of all deaths in 2018.<sup>3</sup> However, this novel practice remains controversial. Concerns have been raised about whether patients might request MAiD solely because of poor access to palliative care, or because of social or economic vulnerabilities.<sup>4</sup> Concerns have also been

expressed about potential barriers to accessing MAiD<sup>5</sup> due to geographic location, provider or institutional conscientious objection, or administrative delay.<sup>6</sup> Using data collected by the Office of the Chief Coroner for Ontario (hereafter, the “Coroner’s Office”) and population-based health administrative data, we sought to describe Ontario’s early experience with MAiD, including the demographic and clinical characteristics of MAiD decedents in comparison with those of the general population of decedents in Ontario, to address the expressed concerns about MAiD.

## Methods

### Design

We conducted a retrospective cohort study involving all patients who received MAiD and all other decedents in Ontario, Canada, between June 7, 2016, and Oct. 31, 2018. We used data from the Coroner’s Office (MAiD decedent cohort) and population-based health administrative databases that include data on all Ontario residents (Ontario decedent cohort).

### Setting

Ontario is the most populous of Canada’s 13 provinces and territories, comprising 14.5 million residents (39% of the Canadian population).<sup>7</sup> It covers a large geographic area, with most Ontario residents (85%) living in urban settings in the Great Lakes area.<sup>8</sup> The largest proportion of MAiD deaths in the country has occurred in Ontario.<sup>3</sup>

### MAiD decedent cohort

A detailed description of Canada’s MAiD legislation and the process of MAiD assessment and oversight in Ontario is available in Appendices 1 and 2, available at [www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.200016/-/DC1](http://www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.200016/-/DC1). All MAiD deaths between June 17, 2016, and Oct. 31, 2018, were included in the MAiD decedent cohort. All Ontario MAiD deaths must be reported to the Coroner’s Office, which serves as the provincial data custodian for the purpose of monitoring compliance with the federal MAiD legislation on behalf of the government of Ontario.<sup>9</sup> A standardized reporting process for all MAiD deaths was established by the Coroner’s Office<sup>10</sup> (Appendix 2) to collect data about each MAiD death from patient records and telephone communication with MAiD providers and the patients’ next of kin, including clinical and demographic information about the deceased, details about MAiD eligibility, information about the clinicians who assessed and provided MAiD, and any concerns raised by family members or the MAiD providers (e.g., perceived delays in access). Although Canadians do not require a specific prognosis to be eligible for MAiD — only that their natural death is reasonably foreseeable (Appendix 1) — prognostic estimates were generated from clinical notes recorded as open text for each MAiD case when possible. Prognostic estimates were categorized as less than 1 month, 1–6 months or more than 6 months. Quantitative estimates or ranges in the clinical notes were sorted into the appropriate category. When specific numbers were not provided in the clinical notes, “hours,” “days” or

“weeks” were coded as less than 1 month, “months” as 1–6 months, and “months or years” as more than 6 months. Any unclear, discrepant data or clarifications were discussed and resolved by consensus between 2 authors with relevant clinical expertise (J.D. and R.H.).

### Ontario decedent cohort

All Ontario population decedents (including those in the MAiD decedent cohort just described) between June 7, 2016, and Mar. 31, 2018, were identified using population-based routinely linked health administrative data sets on all Ontario residents. These data sets were linked using unique encoded identifiers and analyzed at ICES, a not-for-profit, provincially supported research institute ([www.ices.on.ca](http://www.ices.on.ca); see Appendix 3, available at [www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.200016/-/DC1](http://www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.200016/-/DC1), for a list of databases included). Individuals who were enrolled in the provincial health insurance plan for less than 6 months were excluded to ensure the availability of demographic data to describe and characterize decedents. Patient and demographic characteristics included age, sex, income quintile and location of usual residence (based on decedents’ postal code at the time of death and Canadian census data), marital status, and location and cause of death; complete data on marital status and cause of death were available only between June 7, 2016, and Dec. 31, 2016 ( $n = 54\,825$ ).

### Purpose

The primary purpose of this study was to describe the demographic and clinical characteristics of the MAiD decedent cohort compared with all Ontario decedents. Given the primary purpose, and in view of the concerns outlined in the introduction, the secondary purpose was to describe demographic and clinical characteristics of MAiD deaths associated with a shortened reflection period and difficulties accessing MAiD as reported by family members.

### Statistical analysis

Descriptive statistics were used to characterize the decedent cohorts. We expressed continuous variables as means and standard deviations or medians and interquartile ranges, and categorical variables as frequencies and percentages. Comparisons between MAiD and Ontario decedent cohorts were evaluated using standardized differences,<sup>11</sup> with a standardized difference of less than 0.1 indicating small differences. We examined between-group differences within the MAiD cohort using the Student *t* test, the Wilcoxon rank-sum test and the  $\chi^2$  test as appropriate. For the MAiD cohort, we also performed prespecified unadjusted logistic regression analyses to describe the association of different demographic and clinical factors with shortening of the usual 10-day reflection period and clinician- or family-reported difficulties in accessing MAiD. Missing data were included in counts and comparisons when possible. We also examined these relations using unadjusted modified Poisson regression analyses to estimate relative risks.<sup>12</sup> All statistical analyses were performed using SAS Enterprise Guide version 7.12 (SAS Institute).

## Ethics approval

This study was approved by the Health Sciences Research Ethics Board at the University of Toronto (protocol no. 35470).

## Results

A total of 2241 patients were included in the MAiD cohort and 186 814 in the general Ontario decedent cohort (Table 1). The median age of MAiD recipients was 75 years (range 22–105), and 50.2% were women. Most patients had cancer (64.4%) as their diagnostic indication for MAiD, followed by neurodegenerative (11.9%), cardiovascular (8.5%) and respiratory disease (7.5%). Nearly half (48.5%) of MAiD recipients were married, 25.7% were widowed, and 16.6% were separated, divorced or single. Most patients (84.7%) resided in a private residence before receiving MAiD, and 6.3% resided in an institutional setting (long-term care or complex continuing care facility). Only 14.9% resided in a rural setting. Medical assistance in dying was performed predominantly in a private residence (45.0%) or acute care hospital (40.9%), with the remainder in residential care settings (e.g., long-term care). Compared with all Ontario decedents, MAiD recipients were younger (74.4 v. 77.0 yr, standardized difference 0.18); more likely to be from a higher income quintile (24.9% v. 15.6%, standardized difference across quintiles 0.31); less likely to reside in an institutional setting (6.3% v. 28.0%, standardized difference 0.6 for place of residence); more likely to be married (48.5% v. 40.6%) and less likely to be widowed (25.7% v. 35.8%, standardized difference 0.34 for marital status); and more likely to have a cancer diagnosis (64.4% v. 27.6%) and less likely to have cardiovascular disease (8.5% v. 27.8%) listed as the cause of death (standardized difference 0.88 for type of illness).

Patients receiving MAiD commonly reported both physical (99.5%) and psychologic (96.4%) suffering (Table 2). Only 1 patient received self-administered MAiD; the remainder were physician-administered. Palliative care providers were involved at any point in the care of 77.2% of patients, and at the time of the request for MAiD in 74.4%. Psychiatric consultations were performed in 6.2% of cases. In 4.3% of cases, the MAiD recipient had been found ineligible for MAiD on a previous request. In 36.3% of cases, the MAiD recipient had a pre-existing clinical professional relationship with the MAiD provider or one of the assessors. Prognostic estimate of remaining life was not recorded for 56.0% of MAiD recipients, but it was 6 months or less for 883 patients (89.5% of those with a recorded prognosis). Medical assistance in dying was performed by a physician in 94.4% of cases and by a nurse practitioner in 5.6% of cases.

**Table 1 (part 1 of 2): Characteristics of all decedents in Ontario and decedents who received medical assistance in dying**

Characteristic	No. (%) of decedents*		Standardized difference (Ontario v. MAiD)
	All Ontario n = 186 814*	MAiD n = 2241*	
Age, yr, mean $\pm$ SD	77.0 $\pm$ 15.6	74.4 $\pm$ 13.1	0.18
Sex, female	92 270 (49.4)	1124 (50.2)	0.02
Income quintile			0.31
1 (lowest)	48 786 (26.1)	383 (17.1)	
2	41 468 (22.2)	414 (18.5)	
3	35 566 (19.0)	416 (18.6)	
4	31 284 (16.7)	449 (20.0)	
5 (highest)	29 153 (15.6)	559 (24.9)	
Missing	557 (0.3)	20 (0.9)	
Rural residence			0.03
No	160 847 (86.1)	1898 (84.7)	
Yes	25 456 (13.6)	333 (14.9)	
Missing	511 (0.3)	10 (0.4)	
Metropolitan influenced zone†			0.07
Strong (more urban)	71 315 (38.2)	823 (36.7)	
Moderate	35 244 (18.9)	459 (20.5)	
Weak	57 297 (30.7)	638 (28.5)	
None (more rural)	22 878 (12.2)	311 (13.9)	
Missing	80 (0.0)	10 (0.4)	
Place of death/MAiD			0.25
Home/private	87 123 (46.6)	1008 (45.0)	
Hospital	74 828 (40.1)	917 (40.9)	
Long-term care	15 313 (8.2)	89 (4.0)	
Other	9550 (5.1)	227 (10.1)	
Marital status‡§			0.34
Single	5824 (10.6)	117 (7.2)	
Married	22 256 (40.6)	791 (48.5)	
Divorced/separated	4579 (8.4)	154 (9.4)	
Widowed	19 610 (35.8)	419 (25.7)	
Unknown/other	1838 (3.4)	145 (8.9)	
Missing	718 (1.3)	4 (0.2)	
Place of residence‡			0.6
Noninstitutional settings	134 528 (72.0)	1527 (93.7)	
Private residence		1380 (84.7)	
Assisted living facility		147 (9.0)	
Institutional settings	52 286 (28.0)	102 (6.3)	
Long-term care facility	46 390 (24.8)	79 (4.8)	
Other	5896 (3.2)	23 (1.4)	

**Table 1 (part 2 of 2): Characteristics of all decedents in Ontario and decedents who received medical assistance in dying**

Characteristic	No. (%) of decedents*		Standardized difference (Ontario v. MAiD)
	All Ontario <i>n</i> = 186 814*	MAiD <i>n</i> = 2241*	
Type of illness§			0.88
Cancer	15 129 (27.6)	1444 (64.4)	
Cardiovascular	15 249 (27.8)	190 (8.5)	
Hepatic	680 (1.2)	9 (0.4)	
Neurodegenerative	6346 (11.6)	266 (11.9)	
Renal	1118 (2.0)	23 (1.0)	
Respiratory	5217 (9.5)	167 (7.5)	
Other	10 341 (18.9)	142 (6.3)	
Missing	745 (1.4)	0	

Note: MAiD = medical assistance in dying, SD = standard deviation.

\*Unless stated otherwise.

†Metropolitan influenced zones are defined by the percentage of residents in the zone who commute to work in the core of a metropolitan area ([www150.statcan.gc.ca/n1/pub/92-195-x/2011001/other-autre/miz-zim/def-eng.htm](http://www150.statcan.gc.ca/n1/pub/92-195-x/2011001/other-autre/miz-zim/def-eng.htm)).

‡For the MAiD cohort, the initial 611 patients were removed from the analysis of this variable because these data were not recorded.

§For the Ontario decedent cohort, complete data on marital status and cause of death were available only between June 7, 2016, and Dec. 31, 2016 (*n* = 54 825).

Palliative care clinicians provided MAiD in 12.8% of cases and were either the provider or an assessor in 19.8% of cases (data not shown). English or French was the preferred language for 90.9% of MAiD recipients. A total of 156 (9.6%) had documented difficulties with communication (e.g., soft voice due to neurodegenerative disease).

The statutory 10-day reflection period was shortened in 26.6% of all cases (Table 3) and in 58.4% (229/392) of those with an estimated prognosis of less than 1 month. The reflection period was significantly more likely to be shortened for patients who were followed or assessed by a palliative care provider (odds ratio [OR] 1.53, 95% confidence interval [CI] 1.20–1.94), and less likely to be shortened for neurodegenerative (OR 0.28, 95% CI 0.19–0.42) or respiratory disease (OR 0.47, 95% CI 0.31–0.71) compared with cancer. The reflection period was also less likely to be shortened for individuals living in an institutional setting (OR 0.65, 95% CI 0.46–0.90), or when the estimated prognosis was 1–6 months (OR 0.12, 95% CI 0.09–0.16) or more than 6 months (OR 0.07, 95% CI 0.03–0.14) compared with a prognosis of less than 1 month.

In 6.6% of MAiD cases, a family member or MAiD provider raised concerns about difficulties accessing MAiD, such as delays in patient referrals to a willing MAiD assessor or provider, or lack of clarity on how to make a request for MAiD. Access concerns were more likely to be reported for noncancer diagnoses (hepatic disease [OR 12.95, 95% CI 3.41–49.13] or “other” [OR 2.06, 95% CI 1.17–3.62]), in cases where there had been a previous finding of ineligibility for MAiD (OR 3.32, 95% CI 1.91–5.79), or a documented communication difficulty (OR 2.23, 95% CI 1.26–3.93). Access concerns were less common when the MAiD pro-

vider or one of the assessors was previously known to the patient (OR 0.56, 95% CI 0.39–0.83) or if the prognosis was 1–6 months (OR 0.55, 95% CI 0.33–0.91) compared with less than 1 month. No specific demographic, geographic or economic characteristic was associated with shortening of the reflection period or concerns about access. The relative risks for each characteristic are provided in Appendix 4, available at [www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.200016/-/DC1](http://www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.200016/-/DC1).

## Interpretation

In this study comparing people who received MAiD in Ontario up to Oct. 31, 2018, with all decedents, we found that people who chose MAiD reported physical or psychologic suffering as the primary reason, despite engagement of palliative care in about three-quarters of patients, which suggests that for many patients the MAiD requests were not because of poor access to palliative care. Recipients of MAiD were younger, had higher income levels, were substantially less likely to reside in an institution and were more likely to be married than decedents from the general population, suggesting that MAiD requests are unlikely to be driven by social or economic vulnerability.

A previous population-based cohort study that compared the demographic characteristics of 1329 Swiss citizens undergoing MAiD with Swiss national census data over a 5-year period found that MAiD recipients were both more wealthy and highly educated, and less likely to be living in an institutional setting, than decedents overall.<sup>13</sup> However, the Swiss context differs from that of Canada in that only self-administered MAiD is permitted (not physician-administered MAiD), and reporting of MAiD cases is not mandatory. Comprehensive data about MAiD recipients in the United States,<sup>14</sup> Belgium<sup>15</sup> and the Netherlands<sup>16</sup> have been available for more than 2 decades. Recipients of MAiD in those jurisdictions had cancer slightly more often (~73%–77%) and cardiac and respiratory disease less often (3%–5%) than MAiD recipients in Ontario.<sup>17</sup> To our knowledge, there is no publicly reported statistical comparison of socioeconomic differences between MAiD decedents and general decedents from these jurisdictions.

Requests for MAiD can be emotionally difficult for patients and family members, and administratively burdensome for clinicians who are helping their patients navigate the assessment process (Appendix 1). Any perceived delays can be upsetting for patients, families and clinicians alike. Reassuringly, only 6.6% of families reported difficulties with access to MAiD, and the frequency of these reports was not affected by socioeconomic or demographic factors, nor were they more common among patients who were assessed or followed by psychiatry or palliative care. Palliative care consultations are one means of ensuring that patients requesting MAiD are aware of the alternative ways to treat suffering, and psychiatric consultations can help to determine whether some patients are capable of making the

decision to have MAiD. Neither palliative care nor psychiatric consultation is mandatory in Canada for patients who request MAiD, and although some have argued for and against mandatory psychiatric assessments,<sup>18,19</sup> the shortage of psychiatric specialists in some regions could make this requirement a substantial barrier to accessing MAiD.

The involvement of palliative care providers in the assessment and provision of MAiD in some patients who received MAiD is noteworthy. The World Health Organization's definition of palliative care<sup>20</sup> excludes MAiD, and the International Association for Hospice and Palliative Care has argued that palliative providers should not be involved in the practice of MAiD, and that "no country ... should consider the legalization of [MAiD] until it ensures universal access to palliative services and to appropriate medications."<sup>21</sup> Internationally, the relation between MAiD and palliative care providers ranges from synergistic and cooperative to conflicted and opposed.<sup>22</sup> Some palliative care providers in Canada believe that MAiD is an important part of their clinical practice<sup>23</sup> and have integrated MAiD with the provision of palliative care.<sup>24</sup> Others have expressed concern that confusion between MAiD and palliative care might discourage the adoption of a palliative approach for those who could benefit.<sup>4</sup> Our data do not support or refute either position, but as in other jurisdictions where MAiD is legal, we found that most MAiD recipients were followed by a palliative care clinician before death,<sup>14,15,21,25</sup> whereas only a minority of Ontario residents are followed by palliative care clinicians before they die.<sup>26</sup> This may allay fears that people are turning to MAiD because they cannot access palliative care. It may also suggest that people may be seeking MAiD to alleviate a type of suffering (e.g., existential distress<sup>27</sup>) that may not be effectively treated by palliative care clinicians.

Another common concern about the legalization of MAiD is the potential for people who face social or economic vulnerabilities to be pressured into MAiD. However, our data indicate that people from traditionally vulnerable demographic groups (from an economic, linguistic, geographic or residential perspective) were far less likely to receive MAiD, consistent with findings from the US and Europe.<sup>13,17,28,29</sup> Whether this reflects a lower desire for MAiD in these demographic groups, or a broader lack of access to end-of-life options for vulnerable

**Table 2: Characteristics of decedents who received medical assistance in dying**

Characteristic	No. (%) of decedents n = 2241
Type of suffering identified on assessment	
Physical	2230 (99.5)
Psychologic	2161 (96.4)
Prognostic estimate	
Not recorded	1254 (56.0)
< 1 month	392 (17.5)
1–6 months	491 (21.9)
> 6 months	104 (4.6)
Preferred language*	
English or French	1482 (90.9)
Other	50 (3.1)
Unknown	98 (6)
Communication difficulties (e.g., soft voice, dysarthria)*	156 (9.6)
Profession of MAiD provider	
Physician	2116 (94.4)
Nurse practitioner	125 (5.6)
Specialty of MAiD provider	
General practice (with no other specialty indicated)	1104 (49.3)
Palliative care (including nurse practitioners)†	287 (12.8)
Anesthesiology	285 (12.7)
Internal medicine and subspecialties	180 (8.0)
Nurse practitioner (without further specialization)	116 (5.2)
Medical or radiation oncology	74 (3.3)
Emergency medicine†	66 (2.9)
Intensive care†	62 (2.8)
Surgical specialties/subspecialties	42 (1.9)
Other	25 (1.1)
At the time of request, the patient was receiving palliative care from a physician or nurse practitioner	1667 (74.4)
Patient followed or assessed by palliative care at any point	1731 (77.2)
Psychiatrist involvement in assessment of MAiD eligibility	140 (6.2)
Patient previously known to MAiD provider/assessor	814 (36.3)
Previous request for MAiD denied	
No	2014 (89.9)
Yes	97 (4.3)
Unknown	130 (5.8)
10-day reflection period shortened	596 (26.6)
Family or care team reported difficulties accessing MAiD	148 (6.6)
Note: MAiD = medical assistance in dying.	
*For the MAiD cohort, the initial 611 patients were removed from the analysis of this variable because these data were not recorded.	
†In Canada, these fields have all been recognized as specialties or subspecialties by the Royal College of Physicians and Surgeons of Canada, but not all providers in these fields have completed an accredited specialty training program. Many providers in these fields have completed nonaccredited training, or have developed a focused practice based on many years of clinical experience.	



**Table 3 (part 1 of 2): Characteristics associated with shortening of the 10-day reflection period or reported problems accessing medical assistance in dying**

Characteristic	10-day reflection period shortened; no. (%) of decedents*		Unadjusted OR (95% CI)	Reported problems accessing MAID; no. (%) of decedents*		Unadjusted OR (95% CI)
	Yes n = 596	No n = 1645		Yes n = 148	No n = 2093	
Age, yr, mean $\pm$ SD	75.0 $\pm$ 12.9	74.2 $\pm$ 13.2	1.00 (1.00–1.01)	74.5 $\pm$ 13.2	74.4 $\pm$ 13.1	1.00 (0.99–1.01)
Sex						
Female	284 (47.7)	840 (51.1)	Reference	73 (49.3)	1051 (50.2)	Reference
Male	312 (52.3)	805 (48.9)	1.15 (0.95–1.38)	75 (50.7)	1042 (49.8)	1.04 (0.74–1.45)
Income quintile						
1 (lowest)	99 (16.6)	284 (17.3)	Reference	27 (18.2)	356 (17.0)	Reference
2	110 (18.5)	304 (18.5)	1.04 (0.76–1.42)	25 (16.9)	389 (18.6)	0.85 (0.48–1.49)
3	106 (17.8)	310 (18.8)	0.98 (0.71–1.35)	28 (18.9)	388 (18.5)	0.95 (0.55–1.65)
4	111 (18.6)	338 (20.5)	0.94 (0.69–1.29)	36 (24.3)	413 (19.7)	1.15 (0.68–1.93)
5 (highest)	162 (27.2)	397 (24.1)	1.17 (0.87–1.57)	30 (20.3)	529 (25.3)	0.75 (0.44–1.28)
Missing	8 (1.3)	12 (0.7)		2 (1.4)	18 (0.9)	
Rural						
No	506 (84.9)	1392 (84.6)	Reference	122 (82.4)	1776 (84.9)	Reference
Yes	85 (14.3)	248 (15.1)	0.94 (0.72–1.23)	24 (16.2)	309 (14.8)	1.13 (0.72–1.78)
Missing	5 (0.8)	5 (0.3)		2 (1.4)	8 (0.4)	
Metropolitan influenced zone†						
Strong (more urban)	214 (35.9)	609 (37.0)	Reference	59 (39.9)	764 (36.5)	Reference
Moderate	108 (18.1)	351 (21.3)	0.88 (0.67–1.14)	21 (14.2)	438 (20.9)	0.62 (0.37–1.04)
Weak	181 (30.4)	457 (27.8)	1.13 (0.89–1.42)	49 (33.1)	589 (28.1)	1.08 (0.73–1.60)
None (more rural)	88 (14.8)	223 (13.6)	1.12 (0.84–1.50)	17 (11.5)	294 (14.0)	0.75 (0.43–1.31)
Missing	5 (0.8)	5 (0.3)		2 (1.4)	8 (0.4)	
Marital status‡						
Single	27 (6.2)	90 (7.5)	0.78 (0.50–1.24)	6 (6.8)	111 (7.2)	0.90 (0.37–2.15)
Married	219 (50.2)	572 (47.9)	Reference	45 (51.1)	746 (48.4)	Reference
Divorced/separated	35 (8.0)	119 (10.0)	0.77 (0.51–1.16)	11 (12.5)	143 (9.3)	1.28 (0.64–2.53)
Widowed	110 (25.2)	309 (25.9)	0.93 (0.71–1.22)	20 (22.7)	399 (25.9)	0.83 (0.48–1.43)
Unknown	44 (10.1)	101 (8.5)	1.13 (0.77–1.66)\$	5 (5.7)	140 (9.1)	0.70 (0.29–1.66)\$
Missing	1 (0.2)	3 (0.3)		1 (1.1)	3 (0.2)	
Place of residence‡						
Private residence	386 (88.5)	994 (83.2)	Reference	78 (88.6)	1302 (84.4)	Reference
Institutional setting or assisted living facility	50 (11.5)	199 (16.7)	0.65 (0.46–0.90)	10 (11.4)	239 (15.5)	0.70 (0.36–1.37)
Type of illness						
Cancer	449 (75.3)	995 (60.5)	Reference	84 (56.8)	1,360 (65.0)	Reference
Cardiovascular	48 (8.1)	142 (8.6)	0.75 (0.53–1.06)	13 (8.8)	177 (8.5)	1.19 (0.65–2.18)
Hepatic	–¶	–¶	NA	–¶	–¶	12.95 (3.41–49.13)
Neurodegenerative	30 (5.0)	236 (14.4)	0.28 (0.19–0.42)	24 (16.2)	242 (11.6)	1.61 (1.00–2.58)
Renal	–¶	–¶	0.78 (0.31–2.00)	–¶	–¶	NA
Respiratory	29 (4.9)	138 (8.4)	0.47 (0.31–0.71)	7 (4.7)	160 (7.6)	0.71 (0.32–1.56)
Other	34 (5.7)	108 (6.6)	0.70 (0.47–1.04)	16 (10.8)	126 (6.0)	2.06 (1.17–3.62)

**Table 3 (part 2 of 2): Characteristics associated with shortening of the 10-day reflection period or reported problems accessing medical assistance in dying**

Characteristic	10-day reflection period shortened; no. (%) of decedents*		Unadjusted OR (95% CI)	Reported problems accessing MAiD; no. (%) of decedents*		Unadjusted OR (95% CI)
	Yes n = 596	No n = 1645		Yes n = 148	No n = 2093	
Patient followed or assessed by palliative care at any point						
No	105 (17.6)	405 (24.6)	Reference	41 (27.7)	469 (22.4)	Reference
Yes	491 (82.4)	1240 (75.4)	1.53 (1.20–1.94)	107 (72.3)	1624 (77.6)	0.75 (0.52–1.10)
Previous relationship with MAiD provider/assessor						
No	391 (65.6)	1036 (63.0)	Reference	111 (75.0)	1316 (62.9)	Reference
Yes	205 (34.4)	609 (37.0)	0.89 (0.73–1.09)	37 (25.0)	777 (37.1)	0.56 (0.39–0.83)
Psychiatrist involvement in assessment of MAiD eligibility						
No	565 (94.8)	1536 (93.4)	Reference	135 (91.2)	1966 (93.9)	Reference
Yes	31 (5.2)	109 (6.6)	0.77 (0.51–1.17)	13 (8.8)	127 (6.1)	1.49 (0.82–2.71)
Prognostic estimate						
Not recorded	288 (48.3)	966 (58.7)		–¶	–¶	
< 1 month	229 (38.4)	163 (9.9)	Reference	39 (26.4)	353 (16.9)	Reference
1–6 months	70 (11.7)	421 (25.6)	0.12 (0.09–0.16)	28 (18.9)	463 (22.1)	0.55 (0.33–0.91)
> 6 months	9 (1.5)	95 (5.8)	0.07 (0.03–0.14)	–¶	–¶	0.36 (0.13–1.04)
Previous request for MAiD denied						
No	546 (91.6)	1468 (89.2)	Reference	121 (81.8)	1893 (90.4)	Reference
Yes	19 (3.2)	78 (4.7)	0.66 (0.39–1.09)	17 (11.5)	80 (3.8)	3.32 (1.91–5.79)
Unknown	31 (5.2)	99 (6.0)		10 (6.8)	120 (5.7)	
Communication difficulties (e.g., soft voice, dysarthria)‡						
No	402 (92.2)	1072 (89.8)	Reference	72 (81.8)	1402 (90.9)	Reference
Yes	34 (7.8)	122 (10.2)	0.74 (0.50–1.11)	16 (18.2)	140 (9.1)	2.23 (1.26–3.93)
Family or care team reported difficulties accessing MAiD						
No	547 (91.8)	1546 (94.0)	Reference			
Yes	49 (8.2)	99 (6.0)	1.40 (0.98–2.00)			

Note: CI = confidence interval, MAiD = medical assistance in dying, NA = not available, OR = odds ratio, SD = standard deviation.

\*Unless stated otherwise.

†Metropolitan influenced zones are defined by the percentage of residents in the zone who commute to work in the core of a metropolitan area ([www150.statcan.gc.ca/n1/pub/92-195-x/2011001/other-autre/miz-zim/def-eng.htm](http://www150.statcan.gc.ca/n1/pub/92-195-x/2011001/other-autre/miz-zim/def-eng.htm)).

‡The initial 611 patients were removed from the analysis of this variable because these data were not recorded.

§Missing and unknown categories combined for odds ratio calculation.

¶Numbers censored owing to small cell size (<5).

Canadians in general,<sup>6</sup> is not clear. We did not have data about physical or other disabilities, although only 6.3% of the MAiD cohort resided in an institution compared with 28.0% of Ontario decedents overall. Our data cannot exclude the possibility that people experienced pressure to receive MAiD, or that this led to MAiD in individual cases.

## Limitations

The MAiD cohort consisted only of completed cases. Available data from other Canadian provinces suggest that as many as 20% of all patients who request MAiD die naturally before they receive it.<sup>3</sup> It is plausible that such patients may have been

more likely to have encountered difficulties accessing MAiD before their natural death, and so our data may not be an accurate representation of the overall patient experience. The new national reporting system in Canada monitors requests for MAiD, and future data analysis may provide better insight into access. Reporting of completed MAiD cases is mandatory throughout Canada. It is possible that some cases were not reported but, given the limited availability of the medications used to perform MAiD in Canada (e.g., intravenous propofol and neuromuscular blockers that are generally unavailable to health care providers outside of the hospital and MAiD process), delivering MAiD without record would be very unlikely. The

practice of MAiD may vary across the country and our findings may not be generalizable; however, we have no reason to believe that the main findings of this study (related to equity and the involvement of palliative care) would be meaningfully different in other parts of Canada.

A number of important patient characteristics were not routinely recorded — for instance, religion, ethnicity or education — which would have provided additional information about the early cohort of MAiD recipients in Ontario. Difficulties with access were reported by a third party (family, friends or clinicians) post-mortem; these reports may not have represented patients' experiences accurately. Finally, the general Ontario decedent cohort included the patients who died from MAiD; however, MAiD patients made up only about 1% of the cohort.

## Conclusion

The practice of MAiD in Ontario is most common among elderly, community-residing patients with cancer, neurodegenerative disease or end-stage organ failure who are in the final months of life. Our findings that Ontario residents who received MAiD were frequently already followed by palliative care providers suggests that MAiD requests are unlikely to be the consequence of inadequate access to palliative care in Ontario. Recipients of MAiD in Ontario were younger, wealthier, more likely to be married and substantially less likely to live in an institution than the general population of decedents, suggesting that MAiD is unlikely to be driven by social or economic vulnerability.

The data presented here do not address the moral question of whether any amount of suffering can justify the hastening of death. However, the growing trend toward legalization and use of MAiD in many parts of the world should prompt the health care and research community to improve our understanding and treatment of the type of distress that leads to a MAiD request. Furthermore, jurisdictions considering legalization of MAiD might find data from countries like Canada (that have taken this step more recently) useful in informing their decisions about legalization of and necessary safeguards for MAiD.

## References

1. *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* (S.C. 2016, c. 3).
2. *Bill 52: an act respecting end-of-life care*. Québec: National Assembly of Quebec; 2013.
3. *Fourth interim report on medical assistance in dying in Canada*. Ottawa: Health Canada; 2019. Available: [www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-april-2019.html](http://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-april-2019.html) (accessed 2019 July 20).
4. Key messages: palliative care and medical assistance in dying (MAiD), May 2019. Surrey (BC): Canadian Society of Palliative Care Physicians; 2019. Available: [www.cspcp.ca/wp-content/uploads/2019/05/CSPCP-Key-Messages-PC-and-MAiD-May-2019-FINAL.pdf](http://www.cspcp.ca/wp-content/uploads/2019/05/CSPCP-Key-Messages-PC-and-MAiD-May-2019-FINAL.pdf) (accessed 2019 July 20).
5. Downie J. *Carter v. Canada*: What's next for physicians? *CMAJ* 2015;187:481-2.
6. Wright AC, Shaw JC. The spectrum of end of life care: an argument for access to medical assistance in dying for vulnerable populations. *Med Health Care Philos* 2019;22:211-9.
7. Table 17-10-0009-01: Population estimates, quarterly. Ottawa: Statistics Canada; modified 2019 Jan. 28. Available: [www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1710000901](http://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1710000901) (accessed 2019 Oct. 19).
8. About Ontario [main page]. Available: [www.ontario.ca/page/about-ontario](http://www.ontario.ca/page/about-ontario) (accessed 2019 Oct. 19).
9. *Bill 84: Medical Assistance in Dying Statute Law Amendment Act*. Toronto: Ontario Hospital Association; 2016.
10. *Process overview and checklist: reporting a MAiD death to the Office of the Chief Coroner of Ontario*. Toronto: Ministry of Health and Long-Term Care.
11. Austin PC. Using the standardized difference to compare the prevalence of a binary variable between two groups in observational research. *Commun Stat Simul Comput* 2009;38:1228-34.
12. Zou G. A modified Poisson regression approach to prospective studies with binary data. *Am J Epidemiol* 2004;159:702-6.
13. Steck N, Junker C, Maessen M, et al.; Swiss National Cohort. Suicide assisted by right-to-die associations: a population based cohort study. *Int J Epidemiol* 2014;43:614-22.
14. Oregon death with dignity act: annual reports. Portland (OR): Death and Dignity. Available: [www.deathwithdignity.org/oregon-death-with-dignity-act-annual-reports](http://www.deathwithdignity.org/oregon-death-with-dignity-act-annual-reports) (accessed 2018 May 5).
15. Chambaere K, Vander Stichele R, Mortier F, et al. Recent trends in euthanasia and other end-of-life practices in Belgium. *N Engl J Med* 2015;372:1179-81.
16. van der Heide A, van Delden JJM, Onwuteaka-Philipsen BD. End-of-life decisions in the Netherlands over 25 years. *N Engl J Med* 2017;377:492-4.
17. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, et al. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *JAMA* 2016;316:79-90.
18. McCormack R, Price A. Psychiatric review should be mandatory for patients requesting assisted suicide. *Gen Hosp Psychiatry* 2014;36:7-9.
19. Ganzini L. Psychiatric evaluations for individuals requesting assisted death in Washington and Oregon should not be mandatory. *Gen Hosp Psychiatry* 2014;36:10-2.
20. WHO definition of palliative Care. Geneva: World Health Organization; 2013. Available: [www.who.int/cancer/palliative/definition/en](http://www.who.int/cancer/palliative/definition/en) (accessed 2019 July 20).
21. De Lima L, Woodruff R, Pettus K, et al. International association for hospice and palliative care position statement: euthanasia and physician-assisted suicide. *J Palliat Med* 2017;20:8-14.
22. Gerson SM, Koksvis GH, Richards N, et al. The relationship of palliative care with assisted dying where assisted dying is lawful: a systematic scoping review of the literature. *J Pain Symptom Manage* 2019 Dec. 24 [Epub ahead of print]. doi: 10.1016/j.jpainsymman.2019.12.361.
23. Buchman S. Why I decided to provide assisted dying: It is truly patient centred care. *BMJ* 2019;364:l412.
24. Wales J, Isenberg S, Wegier P, et al. Providing medical assistance in dying within a home palliative care program in Toronto, Canada: an observational study of the first year of experience. *J Palliat Med* 2018;21:1573-9.
25. Brinkman-Stoppelenburg A, Onwuteaka-Philipsen BD, van der Heide A. Involvement of supportive care professionals in patient care in the last month of life. *Support Care Cancer* 2015;23:2899-906.
26. Brown CR, Hsu AT, Kendall C, et al. How are physicians delivering palliative care? A population-based retrospective cohort study describing the mix of generalist and specialist palliative care models in the last year of life. *Palliat Med* 2018;32:1334-43.
27. Boston P, Bruce A, Schreiber R. Existential suffering in the palliative care setting: an integrated literature review. *J Pain Symptom Manage* 2011;41:604-18.
28. Loggers ET, Starks H, Shannon-Dudley M, et al. Implementing a death with dignity program at a comprehensive cancer center. *N Engl J Med* 2013;368:1417-24.
29. Battin MP, van der Heide A, Ganzini L, et al. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups. *J Med Ethics* 2007;33:591-7.



**Competing interests:** James Downar is currently employed by Bruyère Continuing Care, a Catholic faith-based health care facility; he is a former unpaid member of the Clinicians Advisory Council of Dying with Dignity Canada, a group that advocated for legalization of medical assistance in dying (MAiD) in Canada; and he previously received consultation fees for curriculum development for a MAiD course offered by Joule, Inc. The work presented here does not represent the views of Bruyère Continuing Care, Dying with Dignity Canada, or Joule, Inc. Jennifer Gibson was co-chair of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying (2015), which was commissioned by provincial and territorial governments to develop recommendations for the implementation of MAiD in Canada; she was also chair of the Advance Requests Working Group of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. No other competing interests were declared.

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manuscript, and approving the final version to be published. All authors agree to be accountable for all aspects of the work. James Downar and Jennifer Gibson had full access to the data in the study and have final responsibility for the decision to submit for publication.

**Data sharing:** Requests for data sharing from the MAiD data set may be directed to the corresponding author by email, but are subject to the terms of the data sharing agreement with the Office of the Chief Coroner of Ontario. The data set for the Ontario cohort of this study is held securely in coded form at ICES. Although data sharing agreements prohibit ICES from making the data set publicly available, access may be granted to those who meet prespecified criteria for confidential access, available at [www.ices.on.ca/DAS](http://www.ices.on.ca/DAS).

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